DOCUMENT RESUME

ED 462 818 EC 308 952

AUTHOR	Bach, Michael
TITLE	Agenda for Action: Policy Directions for Children with Disabilities and Families. Children and Family Series.
INSTITUTION	Roeher Inst., North York (Ontario).
ISBN	ISBN-1-896989-56-X
PUB DATE	2000-00-00
NOTE	24p.
PUB TYPE	Guides - Non-Classroom (055) -- Opinion Papers (120)
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	Access to Education; *Agenda Setting; Attitudes toward Disabilities; *Disabilities; *Educational Policy; *Family School Relationship; Foreign Countries; *Inclusive Schools; *Policy Formation; Public Policy; Social Change; Social Integration
IDENTIFIERS	*Canada; Canadian Government

ABSTRACT

In response to the development of a National Children's Agenda (NCA) to improve the well-being of Canada's children, this document presents specific policy goals to ensure the inclusion of children with disabilities and their families in the NCA. These goals include: (1) establishing inclusive values, rights and approaches for healthy child development; (2) enhancing family economic security; (3) ensuring needed child and family supports at home and in the community; (4) fostering inclusive communities; and (5) strengthening civil society. It is argued that achievement of these five policy goals would provide the conditions for children with disabilities and their families to be fully included in Canadian society. Following sections identify what these goals mean, why each goal is important to including children with disabilities, what is needed to achieve the goals, and strategies to be pursued. Guidelines are then provided for building an inclusive NCA, including ensuring a policy framework that is cross-departmental and cross-governmental and identifying stepping stones for longer term reform. Appendices include a position paper calling for the inclusion of all children in the NCA, research findings on supporting families with children with disabilities, and key ingredients for community services. (CR)

Reproductions supplied by EDRS are the best that can be made
from the original document.

ED 462 818

Children and Family Series

Agenda for Action:

Policy Directions for Children with Disabilities and Families

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

BEST COPY AVAILABLE

EC 308952

Beach Institute
ROEHER INSTITUTE

EC 308952

AGENDA FOR ACTION

POLICY DIRECTIONS FOR CHILDREN WITH DISABILITIES AND FAMILIES

Copyright © 2000 L'Institut Roeher Institute

All rights reserved. The use of any part of this publication reproduced, transmitted in any form by any means, electronic, mechanical, photocopying, recording or otherwise, or stored in a retrieval system, without the prior consent of the publisher is an infringement of the copyright law.

Canadian Cataloguing in Publication Data

Main entry under title:
Agenda for action: policy directions for children with disabilities and families

ISBN 1-896989-56-X

1. Handicapped children - Government policy - Canada.
I. Roeher Institute.

HV890.C3A33 2000 362.4'083'0971 C00-932509-3

L'Institut Roeher Institute, Kinsmen Building, York University
4700 Keele Street, North York, Ontario, Canada M3J 1P3
Tel.: (416) 661-9611
Fax: (416) 661-5701
TDD: (416) 661-2023

Institute President
Cameron Crawford

Written by
Michael Bach

Editing and Layout
is five Communications

The recommended citation for this publication is:
Roeher Institute, *Agenda for Action: Policy Directions for Children with Disabilities and Families*. North York, Ont.: L'Institut Roeher Institute, 2000.

TABLE OF CONTENTS

About The Roeher Institute v

Foreword vii

I. Introduction 1

II. Links To Other Social Policy Initiatives 2

III. The Need For More Specific Policy Goals 3

1. Establish Inclusive Values, Rights, and Approaches For Healthy Child Development 5
2. Advance Family Economic Security 6
3. Ensure Needed Child and Family Supports — at Home and in the Community 7
4. Foster Inclusive Communities 8
5. Strengthen Civil Society 9

IV. Moving Forward — Guidelines For Policy Development 10

Appendix A — *Don't Exclude Our Children* 11

Appendix B — Recent Research on Children and Families by The Roeher Institute 14

Appendix C — Key Ingredients for Community Services 16

About

L'Institut ROEHER *Institute*

Canada's National Institute for the
Study of Public Policy Affecting
Persons with Intellectual
and Other Disabilities

L'INSTITUT ROEHER INSTITUTE IS CANADA'S POLICY RESEARCH ORGANIZATION promoting the equality, participation and self-determination of people with intellectual and other disabilities, by examining the causes of marginalization and by providing research, information and social development opportunities.

To fulfill this mandate, The Institute is engaged in many activities: research and public policy analysis; publishing; information gathering and dissemination; and training, education and leadership development.

The Institute acts as a centre for the development and exchange of ideas, all of which are founded on a new way of looking at disability in the context of a strong civil society. It critically examines issues related to the well-being and human rights of persons with disabilities. Based on its examination of these issues, The Institute raises awareness about the barriers that affect people's full participation in society and that prevent them from exercising their rights. The Institute also presents policy and program alternatives.

For more information about The Roeher Institute please contact us at:

Kinsmen Building
York University
4700 Keele St.
Toronto, ON
Canada M3J 1P3
Tel: (416) 661-9611
Fax: (416) 661-5701
TYY: (416) 661-2023
1-800-856-2207
e-mail: info@roeher.ca
http://indie.ca/roeher

FOREWORD

The federal and provincial/territorial governments are developing a National Children's Agenda (NCA) — a "comprehensive strategy to improve the well-being of Canada's children." (*Speech from the Throne, September 23, 1997*). It will be an action plan to guide and coordinate specific policies and investments on services and benefits to children. A vision and broad goals for the NCA were laid out in "A National Children's Agenda: Developing a Shared Vision". The vision emphasizes that all children should be valued as individuals, given opportunity to reach their full potential, be respected and protected, and be nurtured to contribute to society as they grow. Four goals for children's development are outlined to realize this vision — good health, safety and security, success at learning, social engagement and responsibility.

As families who have children with disabilities began learning about The National Children's Agenda they became concerned. The vision and broad goals of the agenda seemed to hold the promise of inclusion. But the assumptions and measures of healthy child development in various background documents equated disability with disease, and set standards for development that many children would not be able to reach.

In response, families issued a loud and resolute call — *"Don't exclude our children"* (See Appendix A). As federal and provincial governments and the voluntary sector meet to further develop the NCA, and the recent *Early Childhood Development* Initiative, the time is ripe to advance a set of policy goals and strategies to ensure that *all children* are included. This document aims to do just that.

The document presents a distillation of research findings and policy directions that The Roeher Institute has developed in the course of its work, notably in this Children and Families Series. The document is intended for use by government officials, parents, voluntary-sector organizations, employers, community groups — all the stakeholders in the well-being of Canada's children.

We would like to thank the parents, researchers, health professionals, advocates, policy analysts and others whose expertise and insights we have had the privilege to draw upon in developing this text.

Cameron Crawford
President

Michael Bach
Vice President

I. INTRODUCTION

This document draws on a number of sources: recent research by The Roeher Institute on children with disabilities and their families that included consultations and interviews with families from across Canada, analysis of demographic surveys and review of current policies (see Appendix B). In addition, it draws on the directions suggested in a number of research studies and policy proposals for child and family policy in Canada. As well, it draws on the "Voices of Families" — stories, concerns and hopes that families across Canada shared in a series of community meetings convened by the Canadian Association for Community Living.

The document lays out:

- links to other social policy initiatives
- specific policy goals to ensure inclusion of children with disabilities and their families in the National Children's Agenda (NCA)
- why these goals are important and strategies to achieve these goals under the NCA
- guidelines for moving policy development forward under the NCA.

II.
LINKS TO OTHER SOCIAL POLICY INITIATIVES

Moving forward on the National Children's Agenda will prove effective in creating a more valued place in Canadian society for children with disabilities only if it is effectively linked with, and informed by, other social policy initiatives.

- *In Unison*, a recent accord of federal and provincial/territorial governments (except for Quebec) provides a "blueprint" for policy development in the area of disability.[1] It makes an intergovernmental commitment to "full citizenship" of people with disabilities and identifies three "building blocks" to guide policy development — disability supports, income supports and employment supports. It states that in order to secure the vision of full citizenship a "healthy infrastructure of disability organizations" is needed.[2]
- The *Social Union Framework Agreement* lays the ground rules for how the federal and provincial/territorial governments will work to establish a social policy framework for Canadians. A stated principle of the *Agreement* is for both levels of government to "work in partnership with individuals, families, communities, voluntary organizations, business and labour, and ensure appropriate opportunities for Canadians to have meaningful input into social policies and programs."[3]
- The *Federal Disability Strategy* is consistent with *In Unison* and the *Social Union Framework Agreement* in its focus on broad principles and process for reform. It makes commitments to building a knowledge base for policy development, enhancing the capacity of the disability community to participate in policy development and maximizing policy coherence in the disability sector so that long-standing disincentives to citizenship and inclusion can be addressed.[4]
- *Working Together* sets out directions for collaboration between government and the voluntary sector. It acknowledges four key roles the voluntary sector plays in Canadian society — providing a vehicle for public policy dialogue, delivering services, engaging citizens "in the building of communities" and building links across diverse communities, cultures, regions and with other nations.[5] It makes recommendations for strengthening capacity of voluntary organizations — locally, provincially/territorially and nationally — so they can play their roles more effectively.

Together, these initiatives affirm:

- disability — first and foremost — is a matter of citizenship and human rights
- a comprehensive approach to disability supports is required to secure citizenship
- needed policy development requires involvement of both levels of government
- collaboration in policy development is needed — involving disability and family organizations, the voluntary sector, employers, community groups and governments
- disability and family organizations must be supported to actively participate.

III.
THE NEED FOR MORE SPECIFIC POLICY GOALS

The broad vision and goals of the NCA and the other social policy initiatives will help to secure the inclusion and value of children with disabilities only if more specific policy goals are agreed to. These goals are:

- to establish inclusive values, rights, and approaches for healthy child development
- to enhance family economic security
- to ensure needed child and family supports — at home and in the community
- to foster inclusive communities
- to strengthen civil society.

Achievement of these five policy goals would provide the conditions for children with disabilities and their families to be fully included in Canadian society. An *inclusive* National Children's Agenda must profile these goals and indicate how they will be achieved.

The following charts identify:

- what these goals mean
- why each goal is important to including children with disabilities
- what is needed to achieve the goals
- strategies to be pursued.

Needed Policy Goals	What it Would Mean to Achieve this Goal
To establish inclusive values, rights and approaches for healthy child development	All children would be valued equally, regardless of genetic or other characteristics, and the disabling barriers they face. Recognized for their inherent dignity, the unique developmental potential and future contribution of all children would be forefront.
To enhance family economic security	Child and family poverty would be eliminated. Labour markets, income support programs, workplaces and family supports would ensure adequate household income, and the flexibility to provide needed care and nurturing for all children.
To ensure needed child and family supports — at home and in the community	Children and families would not be left alone, without personal supports to meet needs and develop capacities. Supports would be provided in a way that strengthens citizenship — flexibility, responsiveness, portability of supports and direct accountability to families.
To foster inclusive communities	Communities — services and structures and informal social networks — would value and include all children and families. Generic community services, schools, health care, recreation and the built environment would be designed and would operate, inclusively.
To strengthen civil society	The democratic participation that creates citizenship and social cohesion would expand. Decision making in voluntary agencies, schools, hospitals and government bodies would be democratized to include diverse family perspectives. Family organizations would be strengthened and their participation supported.

BEST COPY AVAILABLE

1. Establish Inclusive Values, Rights and Approaches for Healthy Child Development

Why this goal is important	Strategies to pursue under the NCA
The current framework of healthy child development equates disability with disease, and establishes "readiness to learn" indicators of language, cognitive and physical development which many children with disabilities are unable to meet.	1. Promote NCA in a way that includes positive messages about children with disabilities, and that affirms a model of child development based on "unique developmental paths". Recognize, with current child development research, that each child has a "unique developmental path", and that establishing fixed norms of development will devalue some children.
Because of this, children with disabilities are devalued, left powerless, denied opportunities to develop and left without the support they and their families require.	2. Consolidate the knowledge base for this inclusive approach to healthy child development and revise "readiness to learn" indicators accordingly.
For many, the consequence is family breakdown, parental ill-health, overrepresentation in child welfare systems, neglect, abuse and even murder of children with disabilities.	3. Develop clear guidelines for child development services (early intervention, parent resource centres, child care, primary education) that: emphasize inclusive values and rights and indicate how to provide services that promote and nurture unique developmental paths for all children.
Pressures to establish a "compassionate murder" defence and guidelines for "mercy killing" hide our collective failure to ensure all children are valued, protected, safe and supported.	4. Ensure that compassionate murder defence and mercy killing are not used to justify taking the lives of children with disabilities.
The vast expansion of genetic research, screening and testing threatens to "geneticize" and devalue children with disabilities even further.	5. Continue working to ensure that children and youth with disabilities are heard in the justice system.
Canada has not done well in securing the rights of children with disabilities — as indicated in a recent report on Canada and the UN Convention on the Rights of the Child.	6. Prepare an intergovernmental response outlining how Canada will improve its record on children with disabilities under the UN Convention on the Rights of the Child, and meet its obligations under the Universal Declaration on the Human Genome and Human Rights to promote the principles of human dignity, diversity, uniqueness and rights regardless of genetic characteristics.

BEST COPY AVAILABLE

2. Advance Family Economic Security

Why this goal is important	Strategies to pursue under the NCA
Almost 30% of children with disabilities live in poverty.	1. Provide expanded parental leave for parents with a child with a disability, and employment standards to ensure workplace flexibility for parents.
They are twice as likely as other children to live in families where the main income is social assistance or another form of government or income transfer.	2. Clarify and regulate that parents with children with disabilities cannot be discriminated against in employment practices — hiring, advancement, benefits and insurance coverage.
Their parents are twice as likely as other parents to run out of money to buy food.	3. Provide tax incentives, information resources and training for employers in supporting employees who have children with disabilities.
Parents are more likely to leave paying jobs or take lower paying and less secure work when a child is born with a disability in order to provide needed care.	4. As part of home care policy, recognize and financially support (e.g. through expanded tax and employment insurance measures) the unpaid work of caregiving for a child with a disability, where this means a parent stays out of the paid labour market to do so.
Paid jobs that provide the needed flexibility and supports to families are scarce.	5. Provide enhanced income benefits to parents on social assistance caring for children with disabilities; ensure that exemptions from workfare are provided; and ensure that income and assets tests do not further undermine family security and supports (e.g. limiting home ownership or car ownership for eligibility purposes).
Parents have faced exclusions from benefits and employer-based insurance because their child has a disability.	6. Support parents on social assistance wishing to make the transition to paid work — through child care benefits, training allowances and home care supports.

BEST COPY AVAILABLE

3. Ensure Needed Child and Family Supports — at Home and in the Community

Why this goal is important	Strategies to pursue under the NCA
Children with disabilities face physical and social barriers to inclusion in schools, recreation and the life of their communities. Social isolation often begins at a very young age for children with disabilities. As a result, their developmental potential is threatened. The future contributions they can make, with all the value that can bring, is placed at risk. Mothers caring for children with disabilities provide an average of 50-60 hours per week in disability-related care in addition to domestic work, care of other children and work in the paid labour market. As a result, their health status tends to be significantly lower than that of other mothers, the levels of stress and "burnout" much higher. Families are unable to obtain the level of in-home and out-of-home respite and other supports they require. Families caring for children with disabilities are much more likely to break down than other families. Children with disabilities are highly overrepresented in child welfare and protection systems (at an estimate of over 50% in Alberta for example).	1. Make planning supports available and accountable to families with children with disabilities to assist in creating a vision for a child's future, identifying needs, developing personal networks and supports and accessing and coordinating services. 2. Establish integrated, individualized, and flexible respite supports (in-home, out-of-home, associate family, emergency). 3. Enable families to purchase or access needed personal supports, aids and devices and home adaptations in ways that ensure families exercise direction and control over supports. 4. Reverse the trend to tighten eligibility criteria for in-home supports that increasingly restricts supports to those with "severe" disabilities — recognizing the costs that such restrictions bring — to mothers, expanded use of child welfare systems and institutionalization of children. 5. Create funding mechanisms for in-home and community support workers to address the high turnover and inadequate supports resulting from low wages and benefits, lack of worker compensation coverage and inadequate training and professional development. 6. Integrate planning supports and provision of in-home and community access supports into home care policy development to ensure more universal coverage.

4. Foster Inclusive Communities

Why this goal is important	Strategies to pursue under the NCA
Governments, service systems, schools and community agencies continue to create communities that are exclusive. Individualizing needed personal supports (human supports, aids and devices, technological adaptations, home renovations, etc.) help to meet the needs of children and families. But this is not enough. Exclusion will persist unless community services — from schools to recreation to hospitals to transportation systems — exercise leadership for inclusion-practice and universal design. Only 16% of children with disabilities are taught exclusively in regular classrooms. Almost 60% attend regular schools with varying degrees of special or segregated classes. One in ten are taught primarily in segregated classes or schools.[6] Evidence clearly shows that exclusionary education contributes to social isolation, limits developmental potential and diminishes respect for diversity. Some child development services demonstrate inclusive practice — including early child education, child care and parent resource centres. However, this remains more the exception than the rule. Early intervention services and needed health support services (speech, physio, mental health) are essential. However, they are not universally accessible, coordinated, or integrated — home to community to school.	1. Establish accessible, coordinated and integrated child development services — early intervention, child care parent resource centres, pre-school and school-based health support services. 2. Ensure accessible childcare services including afterschool care for children with disabilities beyond the age of 12. 3. Assist child development services in creating the "ingredients" of inclusive practice (See Appendix C). Regulate, invest in professional development, create early identification and assessment tools consistent with an inclusive child development model and provide information and staff supports. 4. Create a pan-Canadian legislative agenda for inclusive education that provides the means to vastly improve the record on the right to education. 5. Make inclusive built environments a cornerstone of community infrastructure initiatives. Provide the necessary enforcement of barrier-free guidelines and codes, and the information and resources needed. Use universal design principles. Encompass schools, parks, recreation centres, health services, transportation systems and child development services in such initiatives. 6. Create focused community partnership initiatives to create shared leadership for the inclusion of children with disabilities. Use the recent national "Community Inclusion Fund" as a potential model.

5. Strengthen Civil Society

Why this goal is important	Strategies to pursue under the NCA
The voices of families caring for children with disabilities have been heard to some extent, but their role in child and family policy and program development is very limited. Families face a piecemeal, fragmented incomplete system of supports and services, some of which entrench exclusion, some which advance inclusion. Strong family organizations, with resources to participate in policy development, and to bring their understanding of the current limitations are needed. Policy and program development, and service delivery in child and family services, both generic and disability-related, are undergoing massive restructuring. Health and social service authorities are regionalizing. Some provincially-funded services are being downloaded to municipal levels. Organizations representing children with disabilities and their families have been weakened by cutbacks in recent years, making participation in a more localized policy development process more difficult. Community services — delivered by the voluntary sector — have not been fully democratized. The voices and concerns of families of children with disabilities have not been adequately represented. The same holds true for school boards, recreation centres and health care facilities.	1. Make democratization of communities — in ways that enhance respect for diversity and social cohesion — a "plank in the platform" of a National Children's Agenda. Develop resources on democratic participation for use by child development services, schools and other community services. 2. Develop educational and information resources to strengthen the "full citizenship" of children and parents. Widely distribute information about the rights of children and parents, and what these mean where disability is involved. 3. Canvas family organizations representing children with disabilities to identify best practices in engagement in policy and program development, and needs for participation. 4. Ensure family organizations are represented at all levels of design and implementation of the National Children's Agenda. 5. Create funding mechanisms to ensure adequate resources to provincial/territorial and national family organizations to participate over the long term in the development and implementation of the NCA. The primary reliance on project funding is severely limiting the capacity of such organizations to provide needed policy advice, knowledge and perspective on the issues of children with disabilities and their families.

IV.
MOVING FORWARD — GUIDELINES FOR POLICY DEVELOPMENT

In order to move forward on the five policy goals, shared assumptions and commitments are key. All stakeholders — the voluntary sector, family organizations, governments, employers, community agencies — need to commit to the following guidelines as a starting point for building an inclusive National Children's Agenda:

- Guidance by a principle of the equal value of all children, regardless of genetic characteristics, gender, ethnicity, race, religion, nationality, language, physical or intellectual disability is paramount.
- No one measure, in any one policy domain, will create a comprehensive Children's Agenda.
- Building a policy framework that is cross-departmental and cross-governmental is key.
- Recognizing the shared responsibility of families, employers, communities and governments is essential.
- Commitment by all stakeholders to a viable process for reform is a necessary condition.
- Identifying what can be done in the short term, as stepping stones for longer term reform, will make for a viable Agenda.
- Ensuring support to family and disability organizations so they can actively participate in policy development is required.

Endnotes

[i] The *In Unison Agreement* was signed in 1998 by federal, provincial and territorial ministers responsible for social services. The Quebec government chose not to participate in the development or signing of the Agreement because it wishes to exercise control over disability-related policy and programs.

[ii] See Federal/Provincial/Territorial Ministers Responsible for Social Services (1998). *In Unison: A Canadian Approach to Disability Issues* (Ottawa: Human Resources Development Canada).

[iii] See *A Framework to Improve the Social Union For Canadians: An Agreement between the Government of Canada and the Governments of the Provinces and Territories, February 4, 1999.*

[iv] See Human Resources Development Canada (1999). *Future Directions.*

[v] Canada. (1999). *Working Together: A Government of Canada/Voluntary Sector Joint Initiative* (Ottawa: Voluntary Sector Task Force, Privy Council Office, Government of Canada).

[vi] Statistics Canada. (2000). "Diversity in the Classroom," *Quarterly Review 2000*, Volume 6(2); Canadian Institute of Child Health (1994). *The Health of Canada's Children, A CICH Profile, 2nd Edition,* (Ottawa: Author). See also Canadian Institute of Child Health (2000). *The Health of Canada's Children, 3rd Edition,* (Ottawa: Author).

APPENDIX A

DON'T EXCLUDE OUR CHILDREN: INCLUDE ALL CANADA'S CHILDREN IN THE *National Children's Agenda*

Parents and advocates of children and youth with disabilities respond:

As parents and advocates of children and youth with disabilities, we are responding to the federal government's *National Children's Agenda* and, in particular, to the *Search for Potential Issues* for the *Centres of Excellence for Childrens Well-Being*. We are alarmed that their current direction does not include or reflect the reality of children and youth with disabilities. Nor is the direction in keeping with treaty rights, the *Charter of Rights and Freedoms* and the United Nations *Convention on the Rights of the Child*. It ignores the social advances that have been made in Canada on behalf of people with disabilities. It places us in danger of losing what we have achieved for our children and youth, and puts the validity of their lives in question.

Children and youth with disabilities shut out of initiative

The *Centres of Excellence* as currently conceptualised will not improve our understanding of children and youth with disabilities and what they need to develop in healthy ways. Both the conceptualisation of the initiative and the process of search for potential issues violate treaty rights and the *Charter of Rights and Freedoms'* promise of equal benefits.

The issues identified in the Discussion Paper, *Fostering Knowledge Development on the Health and Well-being of Children in Canada*, are based on literature that, by definition, implicitly and explicitly excludes children and youth with disabilities from being considered healthy. This definition equates:

- healthy child development with "normal" child development
- disability with costs to the health care system, to the education system, to the community and social service system, to employers
- children who are "Ready to Learn" with those who have physical well-being and "appropriate" motor development; emotional health and a positive attitude to new experiences; age-appropriate social knowledge and competence; appropriate language skills; and age-appropriate general knowledge and cognitive skills.

Over all, the definition encourages health prevention measures to eliminate disability.

Thus, the assumptions that underpin the *Discussion Paper* and other documents distributed in the *Search for Potential Issues* package of the *Centres of Excellence for Children's Well-being* are value-laden. They devalue the lives of all children and youth, and in particular those with disabilities.

Process excludes children and youth with disabilities and their families

As well, the very process of the *Search for Issues* makes it impossible to include discussion of the needs of children and youth with disabilities.

- The process builds on a *Framework for Knowledge Development* that sets standards for health in the four main stages of "healthy" child development — standards a child with disabilities may never attain.
- According to the *Screens* proposed for analysing issues, disability can be discussed only as an issue, so that young people with disabilities are pathologized, and there can never be an informed discussion within the *Framework* of the needs of children and youth with disabilities and their families.
- The *Screen* is problematic because, to measure progress, it requires the use of readily available indicators which are all based on standards of health that define disability as unhealthy.
- In the *Suggested Issues Areas* and *Sub-Issues for Platform Statements*, disabilities — and hence children with disabilities — are positioned as undesirable. The discussion around the *Issues* and *Sub-issues* targets disability for elimination. A person with a disability is devalued, in an unconscionable way, by the emphasis on costs to society associated with disabilities as the justification for preventing disabilities.
- The list of *Stakeholders* to whom the package, *Search for Potential Issues*, was distributed for feedback excludes most stakeholders in the disability community. The exclusion of children and youth with disabilities and their families and their organizations does not allow for an informed discussion of their needs, reaffirms the message that their voices have no value, and violates the *Charter* and the democratic process of this country.

We celebrate our children who have called forth our humanity

As families from across Canada who have children and youth with disabilities, we call into question the underlying assumption that in a perfect world there is no disability. From our hearts and experiences, we celebrate all our children — especially those with disabilities — because they have helped us to learn what it is to be truly human. Their gifts, including their fierce determination, have helped us to build better lives and healthier families and communities. The *Centres of Excellence* initiative should celebrate their courage, and use their lives as models of truly healthy development.

Our goal is simple

Our goal is simple. As an integral part of the *National Children's Agenda*, Canadians need:

- to build consensus around a basic understanding of what it means to be human
- to respect the *Charter of Rights and Freedoms* which guarantees equality rights for people with disabilities
- to build consensus around a framework to guide the building of supports in local communities that promote the culture, heritage, language and traditions, meet the needs, and secure the rights of children and youth with disabilities and their families
- to protect the treaty rights of First Nations' children and youth with disabilities and their families and to ensure that their needs are recognized and met
- to apply the framework according to a model of collaboration, partnerships and accountability that crosscuts jurisdictions and sectors and is guided by children and youth with disabilities and their families
- to make the principle of inclusion the prime value in the process for selecting

issues for the *Centres* of Excellence. This would ensure that the voices of those who celebrate the lives of people with disabilities are heard and that all people with disabilities will be included and valued as full citizens of our communities.

It's time to recognize the natural diversity of human life as being essential to embracing our own humanity.

It's time to make things better.

APPENDIX B
RECENT RESEARCH ON CHILDREN AND FAMILIES BY THE ROEHER INSTITUTE

A number of recent research studies conducted by The Roeher Institute inform the policy goals and strategies outlined in this document:

Count Us In: demographic overview of childhood and disability provides an overview of the number of children with disabilities, their household, social, and economic status, and the scale of issues their families face.

Beyond the Limits: mothers caring for children with disabilities is a study based on indepth interviews with mothers caring for children in five provinces — how they are coping; the time they put into caring for their children; the issues they face in accessing services; and the supports their families require.

Finding a way in: parents on social assistance caring for children with disparities reports on interviews with parents on social assistance in British Columbia, Alberta and Ontario, and includes a review of social assistance and child care policies (providing some update to The Institute's earlier national study on children with a disability and access to child care — *Right Off the Bat: A Study of Inclusive Child Care in Canada*). The study examines the realities of life on social assistance when a parent is also caring for a child with a disability, and the challenges faced in trying to get paid work.

When Kids Belong: supporting children with complex medical needs — at home and in the community — reports on an extensive literature review, focus groups and interviews with physicians, other health professionals, hospital-based social workers and parents. It examines the kinds of planning supports needed so that children with complex medical needs can move from acute care to live at home with their families.

Supported Health Planning — a model is based on the research reported in *When Kids Belong*. It outlines a community-based model to assist families, health care professionals and community services build an integrated services and supports system for children with complex medical needs.

Labour Force Inclusion of Parents Caring for Children with Disabilities provides an account of how parents are faring in the paid labour market — the downward career paths many end up following. Drawing on a review of employment practices, *A Guide for Employers* outlines practical measures employers can take to provide parents with the needed flexibilities and supports that assist them in caring for children and holding down a paying job.

Literature Review on School Health Support Services outlines issues in access to services, best practices in delivery and models of coordinated and integrated services.

Genomes and Justice examines the genetic technology revolution and how it is shaping health care decision making when fetuses are identified as having "genetic deficiencies". As a study in ethics, questions are

raised about how genetic differences have become genetic "deficiencies". The report considers the consequences for how children with disabilities are viewed and valued now, and will be in future generations. The study advances a set of ethical principles to guide health care decision making that focus on respect for diversity, non-discrimination and support in decision making.

APPENDIX C
KEY INGREDIENTS FOR COMMUNITY SERVICES

A recent review of literature undertaken by The Roeher Institute identifies "ingredients" of community supports that enable inclusion of children and families. These ingredients include:

- *stated values and commitments*, for full inclusion, respect and support for children and their families
- *status and consumer power* for families and personal networks in decision making about services/supports (through individualized funding, and/or other mechanisms)
- *planning and coordination* assistance directly accountable to families that recognizes the needs and wishes of the family as a whole
- *accessible and accommodating supports and services* (transportation, health services, recreation, etc.)
- *links/referral* to assist in accessing other community resources and services (e.g. through information networks, resource directories, referral services)
- *opportunities for involvement* of families of children with disabilities in directing the organization/agency providing supports (e.g. through board involvement, consultations, etc.)
- *collaboration* between one support/service and other services (sharing information, common planning approach, shared values)
- *staff training and development* to ensure that support is respectful of all children and families and is able to meet needs
- *accountability* mechanisms for holding the providing organization/agency/person accountable for meeting values and commitments to inclusion, respect and support for children with disabilities and their families.

BEST COPY AVAILABLE

U.S. Department of Education
Office of Educational Research and Improvement (OERI)
National Library of Education (NLE)
Educational Resources Information Center (ERIC)

NOTICE

REPRODUCTION BASIS

☐ This document is covered by a signed "Reproduction Release (Blanket) form (on file within the ERIC system), encompassing all or classes of documents from its source organization and, therefore, does not require a "Specific Document" Release form.

☐ This document is Federally-funded, or carries its own permission to reproduce, or is otherwise in the public domain and, therefore, may be reproduced by ERIC without a signed Reproduction Release form (either "Specific Document" or "Blanket").